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Using special interest sessions to design and implement a fatigue management group for people with multiple sclerosis

AIMS AND METHOD

Special interest sessions are a means of developing additional clinical interests in higher specialist training. We investigated the educational value of developing a group treatment programme for people with multiple sclerosis as well as its benefits for participants.

RESULTS

Feedback from those attending the groups indicated the programme was rated highly or very highly. There was a trend towards improvement in quality of life measures.

CLINICAL IMPLICATIONS

The group programme provided an excellent opportunity for shared

interdisciplinary learning. The use of special interest sessions in psychiatry was important in building relationships with a department without direct psychiatric input and allowed the psychiatric trainee to acquire specific disease knowledge.

Special interest sessions are allocated for two sessions per week of higher specialist training in psychiatry. The College advises that these sessions can be used for clinical interests in addition to the core placement, and interest has been expressed in how these sessions can be used by trainees (Stephenson & Puffett, 2000; Picton, 2002). We wish to report a valuable educational experience in which J.S. used special interest sessions to work within a multiple sclerosis out-patient service, with the aim of developing skills in delivering psychotherapeutic treatments to general hospital patients. The specialist physiotherapist (P.C.) and J.S. worked together to develop and implement a group treatment for fatigue in people with multiple sclerosis.

Fatigue is recognised as a problem in multiple sclerosis: up to 50–60% of people with this disorder identify fatigue as the worst symptom they experience and the one most significantly affecting their quality of life (Branas *et al*, 2000). It is also the least understood of all symptoms (Hubsky & Sears, 1992). Fatigue management programmes have been used in people with multiple sclerosis for a number of years, with some evidence of effectiveness in clinical practice (Schwartz *et al*, 1996; Krupp, 2003; Ward & Winters, 2003). In chronic illness generally, group therapy is commonly used to decrease alienation, facilitate expression of emotions related to the disease and allow participants to learn from each other (Mohr *et al*, 2001). One of the authors (P.C.) has extensive experience in the management of fatigue in individual patients and has previously run fatigue management groups for people with multiple

sclerosis with the help of a client-centred counsellor. The other, J.S., has had experience and training in group analytic psychotherapy and cognitive-behavioural therapy.

Method

The group programme was based on a literature review, experience gained from running a fatigue management programme at 'Revive Scotland' (a charity for multiple sclerosis) and cognitive-behavioural techniques (Box 1). The group met for 2 h, once weekly, for 8 weeks. We chose a semi-structured approach to ensure that specific topics were covered; however, our general philosophy was that a significant proportion of the group time should be unstructured to allow free-flowing discussion. This approach was described to the participants in our introduction, where we emphasised the importance of their contributions.

Group members were recruited from P.C.'s case-load and were suffering from fatigue of a severity that interfered with everyday activity. Referrals to P.C. are from neurologists, whose requests are for treatment of a variety of problems of physical functioning in multiple sclerosis, including fatigue. No specific screening for suitability for group treatment was undertaken; however, P.C. excluded those who had significant cognitive impairment, those she felt would not be suitable for group treatment and those who were not independently mobile with or without aids. Twenty-five people were asked if they wished to participate, and ten were willing and able to attend the group sessions during working



Box 1. Programme of the fatigue management group

Week 1

- Living with multiple sclerosis
- Introduction to fatigue
- Diaries

Week 2

- Review of diaries
- Triggers
- Loss and adjustment

Week 3

- Review of diaries
- Prioritising and flexibility
- Time and energy
- Coping strategies

Week 4

- Review of diaries
- Thoughts and feelings
- Sleeping patterns
- Introduction to goal setting

Week 5

- Goals to enhance quality of life
- Letting go – needs v. wants
- Stress management and relaxation

Week 6

- Review of goal setting
- Strategies to help you achieve
- Physical equipment and environment
- Relaxation

Week 7

- Communication

Week 8

- Review
- Looking to the future

associated problems and losses. Schwartz & Rogers (1994) commented that it is important to address the negative feelings that arise secondary to illness in order to lay a foundation for the further work of the group. This is done by raising awareness of these feelings in everyone and by emphasising the commonality of concerns of group members. Issues such as frustration, anger, guilt, fear of the future and concerns about attitudes of others were raised by the group members. Generally there was a sharing of experiences. The session ended with a brief introduction to the concepts of fatigue, and instruction on completing activity, fatigue and trigger diaries for the following week.

Week 2

There was a consolidation of introductions, including each person describing an interest of theirs. The purpose of this was to encourage members to introduce an identity independent of their illness. Weekly diaries were reviewed, looking at activities, fatigue and triggers. Awareness was raised of associations between physical and mental activity, including stress, and fatigue. Group members seemed most surprised at the links they found between mental stresses and subsequent physical fatigue. Often it was mental stress that led to the most severe fatigue. General discussion continued regarding the losses and difficulties associated with multiple sclerosis.

Week 3

Weekly diaries were reviewed again, and group members were encouraged to take a problem-solving approach to what they were learning about their fatigue. We provided practical suggestions regarding energy conservation, coping strategies and stress management. Blocks to changing behaviour also became evident in discussion. In the first three group sessions it seemed important for the group members to share experiences with each other, and this commonality may have been important in building up trust in the group. In subsequent group meetings, however, members were able to bring up more personal feelings and there was more questioning of each other in these sessions, for example with regard to raising awareness of blocks to changing behaviour.

Week 4

Weekly diaries were again reviewed, with group members now being able to predict fatigue levels, and discussing the impact of behavioural changes they had tried to make. General discussions centred around the need to accept changes caused by the illness, rather than fighting it, which people found from experience increases stress and worsens symptoms. Group members were keen to learn from others and responded well to suggestions. Goal setting in order to improve quality of life was introduced. The idea of effective goal setting is that it breaks down tasks into smaller challenges, which when achieved lead to an enhanced sense of control.

At times during this and other sessions it was easy for the group to move to a general discussion of external problems such as disabled access, which appeared to be

hours. All had a progressive form of multiple sclerosis, either primary or secondary, and the time from diagnosis varied between 1 and 36 years.

During the course, group members were issued with hand-outs relating to the topics covered, including fatigue management and energy conservation, physical equipment and environment, exercise, stress management and relaxation, goal setting, sleep, thoughts and feelings, and communication. A one-page summary of each group session was also issued to group members the subsequent week. This was a recognition of the importance of the members' contributions during the sessions.

Structure of the programme

Week 1

The first session commenced with introductions and an overview of the course, emphasising the importance of what group members would contribute in order to encourage a self-management philosophy. Following this, a discussion was facilitated between the group members regarding the experience of having multiple sclerosis and



an outlet for emotion related to the illness. This expression of anger could then be highlighted and linked with anger towards the disorder which then allowed the group to move on to discussing their underlying feelings, which also included sadness and grief as well as anger. Although in a short-term, supportive type of group one would not undertake any specific exploration of emotions or defences, we found that some group interpretations were necessary in order to facilitate the recognition of these emotions. Without this it seemed that the group would have kept returning to themes of anger and been unable to move forward with work on making changes.

Week 5

Goal setting was discussed further, using the group to 'brainstorm' challenges brought up, such as planning a holiday, by breaking them down into many small goals. The group members were able to use their fatigue management knowledge and personal experience to help each other with only limited input from ourselves. Again the issue of loss was brought up, and there was a discussion that this is an expected emotion, which seemed to show some shift in the group in their acceptance of feelings associated with the illness. The concept of relaxation linking in with stress management was introduced, and a short relaxation session was conducted with the participants in a seated position.

Week 6

There was a continuation of reviewing goal setting, in which members fed back how their goal setting had gone and what they had learnt. There was an eagerness to find out how others had progressed with their goals, and subsequent learning from these findings. Education was given on physical equipment and practical ways of improving the environment. Relaxation and stress management was then discussed in detail and a 45-min relaxation session was conducted.

Week 7

Relationships with others and communication were discussed, with role-plays to facilitate this. Group members took part in a role-play of poor listening as an exercise with each other. We then role-played a scenario of poor communication with a partner, in the context of carrying out domestic chores, to the group. We used this to highlight patterns of communication that people can fall into and to facilitate discussion of ways of improving communication in this and other scenarios. This led to some animated discussions in which group members recognised particular difficulties, which they were keen to work on changing. It was interesting that all the group

members interpreted different things from the role-play, which in itself highlighted the importance of communication.

Week 8

There was a review of the topics covered over the 8 weeks, with discussion from the group on what they had learned and ways of continuing this in the future. The mood in the group was very positive and group members made arrangements with each other to keep meeting on a regular basis following the end of the programme.

Measures and statistical analysis

We monitored quality of life and coping ability with questionnaires before and after the group programme. The 36-item Short Form Health Survey (SF-36; Ware *et al*, 1993), the Leeds Multiple Sclerosis Quality of Life Questionnaire (Ford *et al*, 2001) and the Coping with Multiple Sclerosis Scale (Pakenham, 2001) were used. Those completing the programme were also asked to complete a feedback form.

Data were analysed with χ^2 tests using the Statistical Package for the Social Sciences, version 10.0 for Windows.

Results

Two members withdrew from the group after attending only two or three sessions each. Possible reasons for this might have been a gender imbalance within the group, difficulties in attending due to employment or different stages of adjustment within the group. The two people who withdrew were at the extremes, within the range in the group, in terms of adjustment to their illness.

Measures

The trend was towards improvement in all measures (Table 1). Little meaning can be taken from these results, however, as we do not have data for the two people who withdrew, and the numbers are very small. Replies on the feedback form indicated that those who had completed the group programme rated it highly or very highly and would recommend it to others. Asked to pick items that they would like more of and those they would omit, no items to omit were highlighted. Group members all requested more of certain topics, and all topics were chosen by at least one person. All answered 'yes' to a question about whether they would like a session for partners.

Table 1. Change in scores before and after treatment

	Leeds Quality of Life Questionnaire (n=8)	Coping with MS Scale (n=8)	SF-36 (n=8)
Mean difference in scores before and after treatment	-1.620	-1.612	-1.400
Significance	P=0.105	P=0.107	P=0.161

MS, multiple sclerosis; SF-36, 36-item Short Form Health Survey.



Discussion

The group provided a valuable insight into the difficulties people have in living with chronic illness, disability and fatigue. Our review of the literature indicated that there were a variety of approaches to managing fatigue in multiple sclerosis that had been shown to have some efficacy. We chose to implement a less structured approach as we both felt that free-flowing discussion, with some input from ourselves along supportive therapy/group-analytic lines, was an important component of treatment. Our belief was that this would allow sharing of experience and improve adjustment. During the group sessions we found that with relatively small amounts of input from ourselves general discussions seemed to be productive in raising relevant issues and allowing some working through of underlying emotions. We were also able to bring in the more structured educational elements, either as they arose in discussion or as specific topics. Overall this approach was acceptable to us and to most of the group members. This less structured and somewhat more exploratory group, however, would not be suitable for all patients, and this may be confirmed by our two withdrawals. The process of documenting the structure of the group has been useful in helping us focus on the various possible therapeutic components of this type of therapy, although the question of what these are is not easily answered.

Recommendations for the future are that increased screening of people regarding their suitability for a group as well as increased planning of the composition of groups may be beneficial. The provision of a more structured fatigue management group as an alternative might also be a worthwhile addition to the service for some. A session that partners could attend was also supported and could be easily added to the programme. Feedback from this group did not clearly indicate any other ways to improve the structure, other than by increasing the length of the course. Feedback from future groups may provide more clarity.

From an educational perspective, one of the main benefits we both experienced from running this group was the opportunity to work closely with a professional from another discipline. This provided an excellent opportunity for shared learning, particularly since our professional backgrounds and areas of expertise were

quite different. We were surprised that our approaches towards running the group were so similar; however, this may be due to having similar previous experience in group psychotherapy. This use of special interest sessions was important in allowing the time to build relationships within a department previously without direct psychiatric input, to acquire specific disease knowledge, and subsequently to develop a collaborative treatment.

Declaration of interest

None.

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